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## Supporting Families of Children with Autism Spectrum Disorder

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*St. Catherine University*

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# Supporting Families of Children with Autism Spectrum Disorder

By

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MSW Clinical Research Paper

Presented by the Faculty of the  
School of Social Work

St. Catherine University and the University of St. Thomas  
St. Paul, Minnesota

In Partial fulfillment of the Requirements for the Degree of

Master of Social Work

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The Clinical Research Paper is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by the research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

### **Abstract**

This qualitative research study examines the challenges that families of children with autism spectrum disorder (ASD) face when implementing their child's treatment objectives. Likewise, this study investigates which strategies families utilize to actively participate in family skill objectives to implement their child's treatment plan. Three caregivers (two women and one man) were recruited from around the state of Minnesota to participate in this study. A series of open-ended and scaled questions were asked of participants and the interviews were audio-taped for transcribing purposes. A literature review was written to highlight some of the expressed challenges and strategies families utilized and faced when implementing treatment objectives and these themes were compared and contrasted to the actual research. Research findings indicated that families were challenged by the availability of their schedules to participate in skill development, by challenges in caregiving for other children who resided in the house, and by their own physical and mental health concerns. The research indicated that some of the effective strategies that families utilized included involving other family members in the participation of family skills, working with therapists to generalize their child's behavior to other contexts and people, and prioritizing time to work with a therapist on skill implementation and development. Being familiar with the challenges families face as well as the strategies they employ to address these challenges are imperative for social workers and other professionals who serve families of children with ASD. It is crucial as professionals to create and reinforce effective family skill development and the successful acquisition and generalization of children's skills.

### **Acknowledgements**

I would like to thank my research chair, Mike Chovanec, Ph.D., LICSW, LMFT for his dedication and support during the process of writing this paper and with preparations for the research presentation. His knowledge and skills with revising and editing my paper were of quintessential importance in helping me complete this research paper. Second, I would like to thank my committee members, Jacki Harth, M.S., BCBA, LP and Janet Anderson, MSW, LICSW who were supportive and present during the revision process as well. Their expertise and commitment to this topic was imperative in helping me formulate my research paper.

I would like to extend a warm thank you to my MSW supervisor, Stephanie Palazolla, MSW, LICSW in her continued support of my topic, my research, and the writing of this paper.

Without her guidance, reassurance, and support this production would be completely impossible. Additionally, I would like to thank my academic advisor and field instructor, Jane Hurley-Johncox, MSW, LICSW, LCSW for her continued support and reassurance that this process would be rewarding. Finally, I would like to thank all of the other research students who completed this process during the same timeframe as me as we were all supportive, understanding, and helpful to each other during this process.

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### **Supporting Families of Children with Autism Spectrum Disorders**

Autism spectrum disorders (ASD) describe a variety of lifelong and pervasive developmental disorders that affect individuals and their family in a variety of ways (Cridland, et. al., 2013). Currently, the Center for Disease Control reports the prevalence of ASD to be one out of 88 individuals (Center for Disease Control, 2014) in the United States. The number of children being diagnosed with an ASD has increased over the past few years. At the current rate, diagnoses for ASD have been up 23% since 2009 as the Center for Disease Control reports. These increases can be attributed to a better understanding of the interplay between genetics and the environment; a greater awareness of the disorder by physicians, teachers, and parents; and by the way children are being tested and diagnosed by clinicians such as psychologists and physicians (“Autism spectrum disorder,” 2014).

Because of the number of children receiving diagnoses the cost of care has been on the rise. The average cost to care for a child with an ASD is estimated to be approximately \$17,000 annually compared to a child without an ASD. These costs include health care, education, ASD-related therapy, family-coordinated services, and caregiver time providing care. In total, the United State’s economic expenditure for the care of a child with ASD in 2011 was \$9 billion (“Autism spectrum disorder”, 2014). More importantly, services for the treatment of ASD have been difficult to access for some families due to the deficit and expenditure of services and due to the increase of the number of individuals affected by ASD. This has become an expedited issue affecting families in the United States. To best support these families it is important to provide support to ensure that a continuity of care and treatment can be implemented to produce the best outcomes for their children. Often times, this is achieved by incorporating a variety of professionals to serve the child as a team with the objective of alleviating the symptoms of ASD. Social work professionals, along with other mental health and medical professionals serve

families and children with autism and are greatly affected by the number of ASD diagnoses. These professionals have advocated for needed critical interventions and services. Social workers are advocates for access to resources for families of children with autism and function as imperative resource links to services for these families. Even more, services for older children with an ASD are harder to locate as these services are typically reserved for young children. Therefore, it is important to link families to these services and provide support to them especially when bolstering their participation. Because the treatment of autism is an intensive process it is crucial to facilitate the caregivers and family members to take a proactive approach to their child's treatment and to maintain and generalize their acquired skills. This greatly influences the continuity of care and treatment for a child's progress and skill acquisition over time and it promotes the best possible clinical outcomes.

This research study identified some of the supports and challenges that caregivers face when implementing their child's family skills training and treatment plan. It also identified in what ways families could be supported in their implementation of the treatment regimen. Further research on this topic will benefit professionals and families alike as it will make aware some of the obstacles families face when implementing their child's treatment plan and some of the needs that families face. Further investigation will highlight some of the supports families need in order to be successful when working with their children for a more integrated treatment approach.

For the purpose of this study this researcher utilized qualitative interviews with caregivers of children diagnosed with an ASD. The intention was to investigate some of the pronounced challenges that impeded caregiver's abilities to implement their child's treatment plan as well as some of the necessary supports needed to assist families in facilitating these treatments.

### **Literature Review**

Autism spectrum disorder (ASD) is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior (“Autism fact sheet”, 2014). When working with families of children who have an ASD it is important to integrate the family into the child’s treatment as it facilitates enduring learning and generalization of the learned skills. Families are an integral part of their child’s treatment of an ASD and supporting families in that respect is vital for the child’s functioning and success. This literature review identified the difficulties associated with receiving an ASD diagnosis and discussed the necessity of autism treatments and the importance of family participation in those treatments. Additionally, this review focused on some of the research that has been conducted that highlights some of the challenges and obstacles families face when implementing their child’s treatment. Finally, this literature review investigated some of the ways families were supported and empowered to conduct their child’s established treatment regimen using family skills objectives.

#### *Obtaining an ASD Diagnosis*

Obtaining an autism diagnosis can be devastating to any family and often times the diagnosis is just the beginning of a family’s journey. Mulligan et al. (2012) described the process of receiving an autism diagnosis as “...a uniquely stressful and emotionally intense experience for families” (p. 313). Often times, families have a sense that something is wrong with their child, but have no insight as to specifically what could be wrong. The authors reflected the response of their sample that “Most parents described a lengthy process of personal and professional inquiry prior to receiving a formal diagnosis” (Mulligan et al. 2012, p. 316). This prompted families to pursue a formal assessment of their child in which families faced a considerable delay when waiting for an assessment team to receive a diagnosis. The authors



continue to highlight some of the difficulties with receiving a diagnosis as the assessment disclosure left them feeling exhausted and overwhelmed with information. When families receive a formal diagnosis, this is when the real emotions are expressed. Parents reported a range of emotions after the diagnosis was given. Reactions ranged from grief and shock to validation, to empowerment (Mulligan et al., 2012). It is evident that the journey to receive a formal diagnosis is grueling for families and receiving a diagnosis is often just the first step.

Additionally, families may further struggle to receive education and treatment surrounding the diagnosis immediately. They may also struggle to secure the available social and emotional resources required to process the diagnosis. Banach et al. (2010) claim:

“Receiving an autism spectrum diagnosis is a significant event in the lives of families. Stressful circumstances related to their child’s behavior, life changes required of adapting to the diagnosis, and difficulty accessing the necessary services and resources to support their family are common experiences” (p. 70).

Further, Mulligan et al. (2012) highlighted that “Parents expressed disappointment, frustration, and confusion with these resources and restrictions as they were confronted with long wait lists, rigid admission criteria, and limited resources amid little professional guidance and continuity across service providers” (p. 312). It is obvious that pursuing necessary treatment for a child with ASD is often times the next step for families yet these families face obstacles when attempting to secure treatment for their child.

### *Necessity of Treatment*

After families receive a diagnosis, it is appropriate that a search of suitable and available services should commence although as aforementioned, this may be a challenge in itself. Fernell et al. (2011) urges that there is a clinical agreement that ASD should be diagnosed early so that interventions can be implemented at the youngest age possible. Many families take this time to research different therapies and resources that are appropriate for their child and their family. A

variety of services are available to children with ASD, ranging from DIR (Developmental, Individual-difference, Relationship-based model) more commonly known as “Floortime” to evidence-based practices such as Parent-Child Interaction Therapy (PCIT) and Early Intensive Behavioral Intervention (EIBI) which is rooted in Applied Behavioral Analysis (ABA). Thomas et al. (2007) identified that “In a national sample of such programs, all included early intervention, individualization, specialized curriculum, family involvement, systematic instruction and intensity of engagement” (p. 819). It is highly important for families to search for resources that are evidence-based and supported by research as not all programs are. This can be challenging for families when they begin their search for appropriate resources as sometimes they are promised improvements from therapies that are not well-supported. It is evident that family involvement is an identified factor in the execution of these interventions and will be the focus of this review.

### *Parental Involvement*

Parental involvement is crucial to the development of a child’s skill set and treatment because parents are involved in the development and implementation of interventions that are formulated for their child’s customized treatment. These intervention procedures are more likely to be used across multiple contexts and people and therefore the child stands a greater chance at acquiring the skills more quickly and utilizing them regularly when parents are incorporated. Further, if these interventions are solely implemented by therapists and other change agents and do not incorporate the family participation the acquisition rate for that child will likely be slower and generalization may not occur. Lastly, supporting families in their interaction with their children promotes that dyadic relationship and helps improve successful interactions between the parent and the child (“Autism Community”, 2010).

*Family Challenges to ASD Treatment*

Parental participation in autism-based services is of central importance because effective Early Intensive Behavioral Intervention (EIBI) may depend critically on close family involvement (Grindle et al., 2009). Solomon and Chung (2012) offer several factors that affect families when attempting to actively participate in treating their child's autism. They explain, "Every aspect of a family life may be affected including sleep, meals, toileting, play, travel, education, and work. There are likely to be multiple interrelated presenting problems (overwhelming schedules, parental conflict secondary to exhaustion and grief, confusion about creating and maintaining a treatment plan, etc.)" (p. 257).

Solomon and Chung (2012) continue to discuss ways that parents face obstacles in their daily lives while raising a child with autism. They continue, "Helping parents stay connected in the face of autism is likely to involve helping them find ways to 'do' their day to day lives as well as they can given the realities of raising a child with autism" (p. 257). Because children with autism diagnoses typically function optimally with a structured environment and schedule, the need for routine is ideal. However, the authors caution that parents can get caught up in the rush of appointment and meetings for their child and ultimately "...become slaves to structure" (Solomon and Chung, 2012, p. 257).

Aside from the day-to-day functioning of a family it is notable that the emotional health of parents of children with an ASD may be compromised as they struggle to accept or process through the diagnosis. Specifically, Grindle et al. (2009) noted that "Mothers of children with autism have been shown to be at a higher risk for clinically significant levels of parenting stress than of those mothers of other children with developmental disabilities" (p. 42). Mothers tend to be more prevalent as the primary caregiver for children with an ASD compared to their male counterparts and this finding allows us to see how an ASD diagnosis can affect mothers more adversely.

Finally, there are other challenges that families face when countered with an ASD diagnosis. These factors involve the level of behavior exhibited by the child and the associated financial burdens imposed on a family as they attempt to locate and fund behavioral services for their child. Solomon and Chung (2012) make the point regarding other research that has been conducted, “Research has suggested that parental stress is strongly correlated, not with the child’s level of impairment, but with the child’s level of negative behavior” (p. 258). Grindle et al. (2009) also report similar findings regarding other research that was conducted on the same topic: “...higher reported stress was associated with higher levels of autism symptomatology in the child receiving EIBI” (p. 43). The higher the level of behavior exuded by their child, the higher levels of stress the parents’ are subjected to and this implies the need for a more comprehensive approach to therapies for both the child and the parents. This situation can become overwhelmingly expensive, thus adding yet another stressor to the family’s functioning.

#### *Family Empowerment and Support*

It is evident that families face a variety of challenges and situations that can hinder their participation in their child’s ASD treatment. Yet, families have also demonstrated resiliency within their family life to seek support and find ways to feel empowered to actively participate in the designated treatment regimen. Grindle et al. (2009) reported that “...adaptive coping strategies, informal social support, and beliefs in the efficacy of the interventions were associated with lower reports of stress” (p. 43).

In addition, the support that families seek during this process can vary depending on the needs of the child and the needs of the caregivers. Banach et al. (2010) expressed how parents reported the usefulness of tailored support in the form of support groups, other social support systems, and community resources. More specifically, when parents attended support groups for parents of children with autism, they reported a greater understanding of their child’s needs

coupled with the feeling of empowerment to support their child. Likewise, these parents reported the welcomed interaction with others who faced similar challenges and that they enjoyed the opportunity to share resources, education, and information about services. Linking families to needed resources and information has been an identified way to bolster families during this time.

Solomon and Chung (2012) discuss the analogy of treating autism and establishing a treatment team as a three-legged stool: the first leg represents the introduction of traditional therapies such as ABA and RDI as previously mentioned; a second leg they suggest that represents biomedical interventions that address the physiological imbalances that underlie autism; and a third leg that represents the emotional support available to parents to help them cope with the autism diagnosis and treatment trajectory. The authors claim that by “Creating a comprehensive treatment plan for their child is part of what helps parents move from crisis to coping and models like the three-legged stool can help overwhelmed parents with that daunting task” (Solomon and Chung, 2012, p. 256).

Additionally, Grindle et al. (2009) noted the added benefit to having established a treatment team in the home. The benefit is that parents reported additional support in the home as a positive feature of the treatment programs and those parents were able to use effective behavior management techniques through observing therapists implementing the child’s treatment. Establishing a treatment team of providers that are working together to minimize the impact of autism can be a very helpful approach for families. The treatment team may assist the family in participating more effectively in the treatment plan by offering additional in-home support and training parents on general skill acquirements. Some of the general types of therapies conducted in the home involve assisting parents with responding to challenging

behaviors from the child, giving instructions, interacting within a play setting, and providing reinforcement for appropriate behaviors, among other targets within prescribed therapies.

### *Summary*

Studies have demonstrated that families face different challenges that hinder their ability to carry out their child's treatment regimen. These factors include: challenges in establishing a regular schedule from which to conduct their days or difficulties diverting from routines; the physical, emotional, and psychological health of the caregiver and the reported levels of stress associated with care giving for a child with an ASD; and the level of aberrant behavior exhibited by the child. These themes have been identified as challenges that families face when attempting to execute their child's treatment and proactively participate in their skill acquisition.

Proactively, parents have noted several strategies that help them participate actively in their child's treatment plan. Such ways include: the use of adaptive coping skills and informal support; support groups for caregivers of children with an ASD and access to other social and communal resources; a coordinated approach to the treatment of autism including behavior therapies, addressing potential biomedical concerns of ASD, and the emotional support provided to caregivers. The aforementioned studies have all highlighted the use of these strategies to be helpful for families when working with their child to implement their treatment plan.

It is obvious that parents face a variety of challenges after receiving an ASD diagnosis and families are in need of resources, information, and support. As professionals who work with families, it is imperative to identify such challenges because these challenges affect the functioning of the caregiver, the family, and ultimately the success of the child. More so, it is crucial that professionals become aware of the ways in which families can become resilient and work to implement themselves into their child's treatment plan for continued success.

### Conceptual Framework

When discussing ways to support families of children with ASD it is important to understand the conceptual framework lens from which we will view this topic. Working with families to support their child with an ASD gives us a better comprehension of the system that is in place. For this research, the Ecological Model, which includes the Systems Theory, will be applied to the family to gain a better understanding of the function of that particular system (Forte, 2007). It will further provide an overview and conceptualization of these systems and the interaction between their environments.

To understand the Ecological Model and more specifically the Systems Theory in relation to social work and families, this review will identify and define its distinguishing features. This theory identifies concepts that emphasize the reciprocal relationships between humans and their environment (Forte, 2007). More specifically, theorists of this paradigm contest that environments consist of various levels within systems and that each system can be affected at the *micro*, *mezzo*, and *macro* level of human relationships to environments. Needless to say, it demonstrates that therapy for a child with ASD can be influenced at all levels to produce treatment outcomes. The *micro* level, for example, may include the therapeutic work done between the child and the parent or the child and the therapist. The *mezzo* level is a relationship between settings that influence the child which would include the therapy that is provided to the child at their school and how parents are included in that treatment. Lastly, the *macro* level includes a generalization to larger contexts which can include laws, stigmas, and culture and how this affects systems and it ultimately affects parental confidence in executing their child's treatment objectives.

To further understand the relationship between humans and their environments, Forte (2007) explains a process known as *transactions* which are "...reciprocal exchanges between

entities in the environment”. An example of this would be the therapeutic work between a child, the parent, and the service provider. The service provider may demonstrate how to respond to a challenging behavior from the child and then may provide direction to the parent on how to implement that skill. All entities are working together in one environment to influence active participation toward the child’s treatment regimen. Further, Stein (1974) explains, “A ‘system’ can be defined as ‘a whole made up of interdependent and interacting parts.” When applied to families this theory allows us to view the interaction between each part and the constituted whole within the context of the environment. More specifically, Friedman and Neuman-Allen (2011) explain, “Systems theory also enables us to understand the components and dynamics of client systems in order to interpret problems and develop balanced intervention strategies, with the goal of enhancing the ‘goodness of fit’ between individuals and their environments (p. 59). We can see how the exchange between humans and their environments at differing levels affects the system in different capacities.

There are two parts of this theory that can be applied specifically to families of children with an ASD. First, this theory is flexible when it comes to the intervention that is applied to a family. This is because it can be used to inform treatments that are directed at the parts, the whole, or both and the theory accounts for the environment that the system is embedded in. When trying to increase family participation in a child’s regimen the treatment can be applied to the child with an ASD. Additionally, the implementation of discrete trials and training can also be directed at the family or parents. Lastly, the treatment can also be applied to the environment which, in turn, affects the system. We may see treatments directed at augmenting the environment to produce behavioral changes from the individual or the family. This can be achieved by creating a space to work on skill development such as a table or workroom. This



flexibility of treatment can target different aspects of a system and can produce effective behavioral changes that may facilitate and reinforce family involvement.

Second, the Ecological Model holds the idea of *equifinality* to be true. This refers to the idea that one can achieve identical results from different initial conditions (Forte, 2007). The aforementioned examples are singular treatment targets that can be altered to produce different behaviors within a system. Additionally, there are several different ways that individuals and the system as a whole can be involved in a change process. Social workers or other therapists may use different approaches to increasing family involvement in a child's treatment. They may work with the family to free up time, to schedule other important appointments around the therapy time, to involve other family and friends to assist with running the house so the parent becomes available, to encourage or assist the family in finding other sources of emotional support, and various other remedies may be explored. Because the challenge of family involvement is multifaceted, the solutions may also be comprehensive and reflect the possibility of multiple solutions to the problem.

It is evident that Ecological Model directly and practically applicable to families of children with ASD. This theory is appropriate to apply to this topic because families are systems which are comprised of its parts. More so, the sum is influenced by the whole and the whole is influenced by the part (Forte, 2007). When specifically applied, the child is influenced by the interaction of the parent and the parent is influenced by the interaction of the child. We can see how the treatment that is given by the parents becomes interrelated to the treatment that the child receives.

The Ecological Model, although useful in social work to understand client systems, does have its strengths and weaknesses as a theory. Considering first the advantages, the Ecological Model is broad enough to apply to several different types of systems. Systems can be families,

or variations of, and this is a population of clients that social workers serve. Second, because of the general application of this theory, it is practical as a generalist practice for social workers to practice and implement. Third, when working with family systems, as we are with families of children with autism, it can be a useful approach to influence interventions. That is, depending on whether the treatment is aimed at the part, the whole, or both, it can imply where the intervention is directed, thus influencing the overall treatment.

The Ecological Model, on the contrary, has several disadvantages. First, the theory itself is very abstract and can be almost too broad to apply specifically. Therefore, this model may not be applicable to all clients and situations. Second, the language that is used to describe and define the theory can be very verbose, meaning, that there is not a clear definition of the theory and that it may take more work to adequately define the approach. Third, the Ecological Model implies that there is an interrelation between parts and their whole. This theory seeks to understand the influence between each and does not observe the part or the whole as a singular unit. Therefore, we cannot make assumptions based on one or the other. With this model when applied to families of children with an ASD, you cannot make observations about the child, the parent, or the family unit individually without considering the other related parts.

The purpose of establishing a conceptual framework in which to view our reality is that it helps us identify important questions to be asking about specific problems. It literally becomes the lens in which we view our problem or question and helps us shape our approach to answering that question or addressing that problem. By applying the conceptual framework, this researcher will utilize the Ecological Model to help in the development of the questions. Finally, conceptual frameworks can also be used to help us analyze data. Specifically, it can help us decipher data that is obtained by inductive analysis from qualitative interviews which this research project will be based upon.

## **Methodology**

### *Research Design*

To date, several qualitative interviews and questionnaires have been conducted to examine the perceptions of families of children with autism and different strategies that families find useful after an ASD diagnosis has been given. For the purpose of this study, this author used qualitative interviews to gain information and research on the different types of challenges families have reported. This allowed for those most affected by an ASD diagnosis to have their voices heard. This study identified the supportive networks and strategies that families have found useful in empowering themselves to participate in their child's treatment objectives. Qualitative interviews gave caregivers an opportunity to identify and explain which struggles affect them and their family as well as an opportunity to describe some strategies that promote their integration into their child's treatment plan. From this, themes were formulated to give a better overview of these challenges and strategies and this information gave a clearer picture of the ways professionals can better assist families providing care for a child with ASD.

### *Sample*

This study utilized a convenience sample to establish a group from which the research was applied. The reason for using a convenience sampling technique was that this type of sampling allows the researcher to utilize current participants who fit the sample criteria and who possess experience implementing family skills objectives (Monette et al., 2011, p. 153). This researcher used this technique for the described purposes to contribute to the overall research project.

The following criteria were used to filter participants and establish a parameter from which the sample was derived. The sample this author used included parent(s) (mothers, fathers, and other identified caregivers such as grandparents) who were caring for a child with a

diagnosis of ASD. The participant was included in the research study when a minimum of one year has passed since the ASD diagnosis was given to the child. The child from whom the caregivers were caring for were under the age of ten years old and resided in the family's household. Likewise, caregivers providing care also resided in the household where services were received. These families received home-based services from a provider of behavior therapy for at least 10 hours a week. This author attempted to use a sample size of eight to ten participants.

### *Protection of Human Subjects*

This research study was submitted for approval to the St. Catherine University Institutional Review Board (IRB) before actual data collection began. The consent form (Appendix B) was explained to every participant and each participant received a copy of the agency involvement and research questions prior to obtaining permission to participate in the study. The consent form explained in detail the purpose, background, and procedures of the research study. This form highlighted the confidentiality and voluntary nature associated with the study as well as the assumed risks and benefits of participating in this research design. Each participant was given the right to withdraw their participation at any time without penalty. Recordings and associated electronic documents were and are currently stored on a USB drive in a locked bin in this researcher's possession. Audio recordings will be destroyed no later than June 1, 2015. Each transcript of the interview is void of any identifying information and names will not be included in the final presentation of the research. Staff of the agency from which participants will be used will not be aware of who participates in the study and who does not.

Additionally, it is noted that this study may have inconvenienced some participants by taking time away from their family. In order to address and mediate this concern, this researcher established two different ways that participants could complete the interview. This included

phone interviews and in-person interviews at the participant's most convenient time and neutral location.

Finally, another risk of participation in the study included emotional grief and stimulation from a caregiver who care gives for a child who received an ASD diagnosis. A debriefing occurred after the interview to check in with the participants about any emotional stimulation that may have occurred during the interview. All participants received additional resources that included: emotional supports that are available to the caregiver and information regarding additional supports for families of children with an ASD diagnosis.

### *Research Setting*

This research setting included an agency that provides family skills training and individual intensive behavioral intervention based off of the principles of applied behavior analysis. This agency is located in a suburb of a large, metropolitan city in Minnesota which serves clients throughout the metro and Greater Minnesota. In order to utilize participants from this agency, a permission letter was sent out in addition to the consent form to obtain permission from the participants to include them in the research. Each research interview was conducted via telephone although the option to meet in person was also available.

### *Instrument*

The instrument that was used in this study was a set of five demographic questions in addition to nine open-ended questions that participants reviewed and responded to during the interview. These questions were created by this researcher to derive information from participants for use in this study. This instrument included questions about challenges families find difficult and strategies that families find useful in implementing their child's treatment plan and were open-ended in nature. Two questions utilized a Likert Scale scaling from one to five

with varying degrees of intensity. Questions were submitted to a professional research committee consisting of three members prior to the participant receiving a copy of such questions. The purpose of this review was to have the questions assessed for leading questions and to increase validity of the research.

### *Data Collection*

The convenience sampling occurred in the following steps: 1.) Psychology staff contacted parents through the agency via email to disperse the research flyer, the permission document, the consent form, and the interview questions; 2.) This researcher was contacted by these potential participants via telephone and requested a signed copy of the consent form before the interview took place; 3.) After the consent form was received, this researcher conducted the interview via telephone using the established questions and audio taped the interview for transcribing purposes.

### *Data Analysis*

Once all data had been collected it was analyzed according to the statistical methods that are reserved for qualitative data analysis (Berg, 2011). This researcher utilized an ordinal method to analyze the collected data. With the use of the Likert Scale, participants were able to respond using a scale from one to five with varying associated responses. Consistencies in data emerged and common themes were identified among the data. The Likert Scale that was included in the interview questions yielded numerical data regarding how intense participants feel about specific challenges and strategies regarding treatment. Additionally, themes were identified and categorized into relevant themes and subthemes giving a broader picture of the research outcomes.

*Researcher Bias*

It is evident that when conducting qualitative research in a preferred study that researcher bias does exist and this occurrence may help or hinder the process and interpretation of the results. This author currently works in an employment setting with families of children with ASD. Further, this researcher works with families to develop skills to better assist their child's development and remediation of the symptoms of autism. Not surprisingly, this proposed topic has stemmed from personal interest and experience. Since a bias has already been established, this author feels she may have more insight about the challenges and supportive networks that families experience. This exposure may aid in finding and conducting research to assist these families in participating in their child's treatment plan. This author's role working with families and children to implement behavior therapy has made this researcher sensitive to the issues affecting these families. Additionally, because this researcher's responsibility is to work with these families to develop skills and to encourage family skills participation, it may benefit this author to have some knowledge regarding the issues families face and working on strategies to promote their participation.

However, because there exists a pre-existing bias on part of this author, that may hinder the process and interpretation of the results. This could occur by finding articles for the literature review that are geared toward issues the families this author currently works with face. Or looking too specifically for other contributing factors versus gathering all broad and objective literature may be considered a hindrance as well. In order to remain objective in this research study, this author utilized a research committee consisting of a research chair and two additional community members who reviewed and provided feedback on research. Because these members reviewed the research and proposal, they were able to provide feedback on the

questions that were asked to the participants and assisted in checking for leading questions. This assisted the research questions in being objective for the participants and the study.



## **Findings**

### **Sample**

Through the recruitment process, approximately one hundred and forty participants had been informed of the study. Finally, approximately 15 people were independently exposed to the study by this researcher to broaden the amount of people who were invited to the study. This researcher utilized professionals who work with families of children with autism to recruit additional participants in order to increase the total number of possible participants. The sample consisted of three parents in the study (See Table 1). Finally the timeframe that the interviews were allowed to take place was approximately two months. All of the potential participants had been notified by this time and had the opportunity to inquire about more information or to participate in the study.

### **Sample Characteristics**

The demographics that resulted in this study reflected more women than men were participants (two women and one man total). Both of the women reported that they were Caucasian and the man reported being African American so only two races/ethnicities were represented in this study. The ages of the child with ASD ranged from five to seven years old and the age of the parent ranged from 34 to 40 years old with the male reporting the oldest age. Both of the women were the mother of the child and the man was the father of the child so only parents were represented in this study as a result of the participation. All three of the individual participants were married and therefore no people who were divorced, widowed, or single were represented in the sample (See Table 1.)

Table 1: *Demographics of Research Study*

	<b>OPTIONS</b>	<b>NUMBER (n=3)</b>
<b>GENDER</b>	Male Female	1 2
<b>RACE/ETHNICITY</b>	African American/Black Caucasian/White	1 2
<b>AGE</b>	30-35 36-40	2 1
<b>RELATIONSHIP TO CHILD</b>	Mother Father	2 1
<b>MARITAL STATUS</b>	Married	3

### **Interview Themes**

A concept was considered a *theme* if two or more of the participants discussed or mentioned the concept in their response. Themes were derived from the interview questionnaires which participants filled out for their participation for the research. Each respondent answered all of the questions and themes emerged from these responses. All of the themes, together, comprise major themes about what families found to be challenges to participation as well as strategies for inclusive participation. For the purpose of this study, direct participant quotes are italicized.

### *Parent Availability*

When asked what participants found most challenging about participating in their child's treatment plan was parent availability for family skills training. Three out of three participants spoke about having the ability to actively participate in the family skills objectives and noted different barriers that affected their participation. Some of these barriers included: parents working in or out of the home, parents not being available when staff are at the house, parental illness or mental health-related issues, and tending to other children. Parents mentioned how they desire to participate for the benefit of the child and the family; however, it became evident that this desire to participate is a major factor that hinders parental participation due to inadequate time. One participant acknowledged,

*I believe it has been challenging for me to participate in the trainings because of the time I am unavailable due to working so much. My wife participates in the trainings and later explains to me what she and the staff worked on (Transcript 1, Page 1, Lines 18-20).*

Another participant expressed,

*Having the desire or ability to participate in the trainings is tough. I let the therapists know that I may not always feel the best to participate in family skills but I try to participate as often as I can despite my own health challenges (Transcript 2, Page 1, Lines 30-32).*

It is possible that parent availability is desired but this also presents a challenge that is a reality for these families.

### *Family Involvement*

When participants were asked which strategies they employed that bolstered their participation in their child's treatment, the theme that emerged throughout the interview process was the inclusion of other family members for support. This included the training of the spouse when they were available, broadening out to grandparents, personal care attendants, and other

family members to assist in the skill trainings. Two of three caregivers across two different questions reported feeling more effective and supported when more family members were involved in the training process and when all members responded to positive and aberrant behaviors in synchrony (See Table 2). One parent stated,

*I believe my son benefits from our participation as it helps him learn in other settings and with other people. I try to make sure my family has the opportunity to participate and learn from the therapist so we can all help him learn (Transcript 3, Page 2, Lines 50-51).*

Another respondent discussed,

*I try to get other family members on board with the trainings so they can respond to different behaviors that [child] displays. It's so much easier to respond to her behaviors when everyone is reacting the same way to them (Transcript 2, Page 2, Lines 47-49).*

By having other significant members of the family involved in the treatment process, this reduced the amount of stress the primary caregiver experienced as well as established a standard response for all members to the child.

### *Generalization of Skills*

When asked about how caregiver's participation has affected their children's skill development and generalization, all three participants discussed how their participation assists their child in generalizing their learned skills to other people and settings. Participants noted that they attempted to be available to participate in family skills to better help their child learn in other settings such as school or the local community. Parents commented that working with a therapist to gain skills helps them interact more successfully with their child in public places as it does with their own child's skill generalization to other settings and people. Parents also identified that including other family members was important to them because it helped the child use their skills with their family members and it promoted consistency of the family responses.

One participant expressed,

*I believe my son benefits from our participation as it helps him learn in other settings and with other people. I try to make sure my family has the opportunity to participate and learn from the therapist so we can all help him learn. My son's skills have started to generalize to his school and I believe holding school staff available to continue to support his skills is important. As far as the community, he has been using his skills in the community and I am better equipped to help him and understand him when things come up (Transcript 3, Page 2, Lines 50-53).*

It is evident that incorporating family members into the treatment plan bolsters support for the child to use their acquired skills.

In contrast, one participant stated,

*He seems to work better with my wife and I feel like I have a harder time understanding what they are doing and how it works. The only challenge I see in the community is that his behaviors have not transferred to the community settings yet and that is challenging (Transcript 1, Page 1, Lines 20-22).*

Although this is the response of one participant, it speaks to the importance of skill practice with others and within different environments to assist in transferring these skills to more natural environments.

Although several themes emerged from the research, not all questions that were asked generated themes across the participants. For example, questions regarding information related to a client's culture and the impact on participation as well as the question asking about any additional information that should be considered or that was not discussed did not yield any themes. The participants did not describe any factors that impacted their participation.

Additionally, the interviews consisted of two scaled questions which asked participants to rate the impact of the challenges and strategies their participation had on their child's skill development and/or their adherence to family skill objectives. These questions were rated by participants on a continuum between a score of 1 (meaning "not at all") to a 5 (meaning "extremely"). No discernible themes emerged from these questions either. It is possible that the

questions did not adequately reflect participant's expressions or that the questions themselves did not yield the results that this researcher had anticipated.

Table 2: *Research Questions & Interview Themes*

QUESTION 1	What challenges, if any, have you faced when implementing your child's family skills training objectives?
THEME	Parent Availability
FREQUENCY	2 of 3 participants
QUESTION 2	What have you found most challenging about implementing your child's family skills training objectives? How did you address this concern?
THEME	Desire to Participate
THEME	Availability to Participate
FREQUENCY	3 of 3 participants
QUESTION 3	In what ways, if any, have these challenges affected your child? Your service providers? Your community?
THEME	Generalization of skills
FREQUENCY	3 of 3 participants
QUESTION 5	What strategies have you used that help you become more participative in your child's treatment objectives?
THEME	Setting priorities
FREQUENCY	2 of 3 participants
QUESTION 7	What assistance would you like to receive that you would find effective in helping you implement your child's treatment objectives?
THEME	Family involvement
FREQUENCY	2 of 3 participants

## Discussion

### *Sample*

Regarding the demographics that resulted in this study, more women than men were participants (two women and one man total). Both of these women reported that they were Caucasian and the man reported being African American so only two races/ethnicities were represented in this study. The ages of the child with ASD ranged from five to seven years old and the age of the parent ranged from 34 to 40 years old with the male reporting the oldest age. Both of the women were the mother of the child and the man was the father of the child so only parents were represented in this study as a result of the participation. All of the individual participants were married and therefore no people who were divorced, widowed, or single were represented in the sample.

The sample was established with the following criteria: 1.) caregivers of a child with an ASD; 2.) the caregiver resided in the same household as the child; 3.) the child had at least one year post-diagnosis of an ASD; 4.) the child and family were receiving at least 10 hours a week of in-home therapy; 5.) and the caregiver was not a current client of this researcher. Out of 155 people who were informed of the research study, only three participants were able to be utilized for the study. Due to the strict nature of the criteria established for the sample, I believe the criteria may have disqualified many families as they did not meet all of the criteria to participate in the study. Some families inquired about participating if they were personal care attendants or teachers of children with ASD but this criterion was not consistent with the sample criteria and therefore these potential participants could not be used.

For families that met some of the criteria, they may have decided they were not eligible and may therefore not have pursued the study. Initially, this researcher needed to be sensitive to the families who may have potentially participated because of the sensitivity around a recent

diagnosis. This lead this researcher to establish criteria that permitted families to pursue the study if at least one year had passed since the diagnosis of an ASD was given. Also, this researcher desired to recruit parents and caregivers of children with ASD who participated in the family skills objectives as this was of central importance to my study and sample. Because of these criteria potential participants who received in-home services but did not participate in family skills objectives were not the target of this study and therefore may not have sought to participate in the study any way. Further, some of the families that received notification regarding the study spoke English as a second language and admitted they did not fully understand the study and therefore this researcher was not able to gain full consent regarding the study and these potential participants were not included in the study.

Finally, taking caregivers away from their duties for their family was a potentially significant deterrent of participants as it a.) Removed the attention and care away from the child and/or family, and b.) The study did not reward participants with any monetary benefit to participate in the study, thus potentially lessening the incentive to participate. The sample that was utilized may represent the caregivers of children with ASD to some degree; however, recruiting participants from this sample may have been too difficult to acquire an adequate sample due to family and time constraints.

## **Themes**

### *Parent Involvement and Challenges*

All three of the families that participated expressed their desire to be participative in their child's treatment plan but they also identified that sometimes challenges prohibited consistent involvement. The literature review highlighted the importance of parental involvement in a child's treatment plan because parents are instrumental in assisting with the development, implementation, and generalization of programming ("Autism Community",



2010). Their participation helps their child achieve more successful acquisition and generalization of skills.

Some of the challenges identified by parents in the study were working during the time staff was implementing therapy, caring for other children in the home, and being completely available when staff are in the home. The literature review, on the contrary, identified ways that families felt challenged which included: busy schedules, parental fatigue, level of child aberrant behaviors, and confusion regarding the implementation of the treatment objectives (Solomon and Chung, 2012). Although the literature review and the reports from parents were different, all of these challenges can be affecting other families as well and must be assessed to determine if these factors are affecting families and their participation. This discrepancy may be due to a larger number of participants in the literature that was reviewed compared to the sample in this research. Additional people may have generated more themes and thus strengthened those themes.

#### *Family Involvement & Empowerment*

One of the main themes that were generated from the interviews was that families found more success in implementing their child's treatment plan when other family members were involved, trained, and participative in the treatment. All three participants touched on this point as important strategies to use; however, the literature review did not discuss specifically the involvement of family members in the treatment process. The literature did review families who reported using external supports such as support groups and other educational resources for support. This indicated that families felt more empowered when they were able to gain access to other resources and education to assist in their participation with their child (Banach et al., 2010; Grindle et al., 2009; and Solomon and Chung, 2012).

Interestingly, the families in the study reported that family involvement was more important than formal supports whereas the literature review revealed that family members were more receptive to other types of help. This discrepancy may be due to the fact that familiar people associated with the family are more important and available in supporting the caregiver and participating themselves. Additional people that are not as available may complicate the matter when more people are involved and it may be more advantageous to have family members on the same page.

#### *Utilization of Resources & Support*

One of the themes that was not represented by the interviews was the notion of utilizing formal support and resources to better cope with care giving for a child with ASD. The literature review highlighted that parents would use support groups, other parents, and other formal resources to better address their concerns and stress about care giving (Banach et al. (2010). However, none of the parents in this study mentioned the use of formal supports to assist with their participation. This may have included additional trainings, support groups, counseling services, or other advocacy group participation as a means to bolster their participation with their child. These services may have helped to address some of the financial, emotional, or care giving stresses that accompanied caring for a child with ASD. Surprisingly, participants did not discuss this aspect of support and the aforementioned time constraints, caring for other children in the home, or busy work and family life may have been extenuating factors. It may have been that families, because they are so busy, do not have additional time to participate in additional services or activities. It may be warranted that more online community support may be beneficial for caregivers in the form of online chat groups, support groups, or access to additional resources that are more accessible from home.

*Caregiver Emotional Stress*

Among the mothers and the fathers in this study, no participant discussed how their stress or emotionality played a part in their participation. Neither of the women expressed this in their interviews as a factor that hindered their participation in their child's treatment plan. The literature review discussed how mothers of children with ASD, more so than fathers, experienced more emotional stress when care giving for a child with ASD especially when they were the primary caregiver for the child (Grindle et al., 2009). It may be possible that since a post-year diagnosis requirement was a criterion point in this study parents may have been less affected by the diagnosis and may have had time to grieve and obtain information and resources.

### Researcher Reaction

One aspect of the study that I found particularly interesting that I had not anticipated was that some people contacted me in attempt to participate in the study but were not entirely sure if the word “caregiver” was synonymous with “teacher,” “staff,” or “Personal Care Attendant.” Unfortunately due to the sample criteria, these potential participants were ruled out and were not included in the study. These participants mentioned they worked in settings with children with ASD and provided care or other services. They mentioned they were involved in some capacity in training the parents to use family skills objectives. However, the criteria that were established strictly attempted to recruit parents/caregivers that participated in the family skills because their *child* was the one receiving the services and attempts to train parents and caregivers was part of the parental training and generalization of skills. It would have been more advantageous to explicitly define the term “*caregiver*” in the recruitment flyer as well as the study information and consent form.

Another aspect of the study I was surprised about was the amounts of participants, or lack thereof, which I received that were eligible to participate in the study. I anticipated eight to 10 participants and only received three appropriate participants. Although I knew the criteria that was established was tight and that the study could potentially inconvenience some parents and caregivers, I fully anticipated that I would receive caregivers who were interested in helping further the study and the field to make it more effective for other caregivers who cared for a child with ASD. This type of study may have been more successful at recruiting families when a financial benefit was arranged as a way to entice families to participate. Because the sample used was sensitive to activities that took them away from their family or work obligations, it may have been productive to include additional ways in which members could participate.

Possibly sending questionnaires via mail or email or establishing other ways caregivers could participate would have been helpful.

Lastly, I anticipated a more in-depth conversation about the challenges and strategies families used to better assist them in working with their children; however, I felt as if families may have been hesitant to offer up these reasons. I anticipated that the interview would be an opportunity for caregivers to explicitly express ways that would make participation more effective for them. Although the research yielded and reiterated some key factors that support families, I do feel caregivers may have been uneasy and hesitant about answering questions regarding the services they were receiving. One possible explanation for this occurrence may have been because I utilized families from my agency of employment and families may have been hesitant to divulge too much information for fear of some agency reaction. The agency information that was distributed informed potential participants of my intention of the study and that their services would not be jeopardized or altered with the agency as a consequence to their participation. Also, potential participants had access to the questions before signing the confidentiality form for them to fully understand what was being asked of them. Finally, the confidentiality form expressed that a participant's decision whether or not to participate will not affect their current or future relations with the University of St. Thomas and St. Catherine University in any way nor will it affect their relations with the agency from which services are received. Future research should address this matter more directly for participants to feel more comfortable about their interviews with agency staff.

## **Limitations and Recommendations for Future Research**

*Language of the study.* During the interview process several potential participants were not sure of the word “*caregiver*” and what exactly it included. This researcher would suggest that this term either be defined or renamed for future research purposes and reported on any research flyers or brochures. This will help eliminate any possible confusion about who is and is not eligible to participate in the study and it will help to tighten the criteria as it will explicitly define the potential participant’s role in the research.

Another issue concerning language that was a limitation of this study was that it was assumed that potential participant spoke and understood the English language. The recruitment flyer, consent form, and questions were all written in English and there was no translation provided for these documents. It is obvious that ASD affects more than just English-speaking individuals and therefore many were not able to participate on the language barrier alone. Several families that met the criteria in the general location that the interviews took place spoke English as a second language and thus did not fully understand the purpose of the study and what the expectation of participation was. This reduced the amount of participants who could participate in the study and this serves as an excellent recommendation for future research to include translations for interview documents to increase a more diversified sample. Although this researcher does not possess statistics regarding families of children with ASD of a different ethnicity, it is plausible that this limitation speaks to the difficulty of accessing these families for further research and development.

*Strict Sample Criteria.* To recapitulate, the sample was established with the following criteria: 1.) caregivers of a child with an ASD; 2.) the caregiver resided in the same household as the child; 3.) the child had at least one year post-diagnosis of an ASD; 4.) the child and family were receiving at least 10 hours a week of in-home therapy; 5.) and the caregiver was not

a current client of this researcher. Out of 155 people who were informed of the research study, only three participants were able to be utilized for the study. Another portion of the study that this researcher believes greatly impacted the amount of potential participants that could have participated in the study was the strict sample criteria. These criteria were established in order to set parameters around which the targeted population was. However, this researcher believes the sample criteria was too narrow and eliminated people who would have been able to participate meaningfully. One recommendation would be to broaden the criteria of the targeted sample and allow for more people to participate. Potentially decreasing or eliminating the criterion for the amount of time since an ASD diagnosis was given as well as modifying or eliminating the criterion for the amount of hours in-home services were received could greatly assist in broadening the sample in future studies. Families received family skills services in a variety of hours during the week. Having an established cut-off reduced the amount of participants that could be utilized because they may have not met this specific criterion.

Difficulties arise with this limitation and recommendation because of the sensitivity surrounding a more recent diagnosis for a child with ASD. In order to address this, all potential participants could receive information and resources regarding a recent ASD diagnosis, additional support services and additional resources for their child, their family, and themselves to address potential emotional concerns for the participants.

*Timeframe of the Study.* Another limitation to the study was the timeline in which respondents were made aware of the research study and the amount of time they had to reply. The timeframe was approximately two months and it may have greatly hindered participants who were not available during that time or were not informed of the study early enough. There was also not a timeframe end specified on the flyer or identified by this researcher so potential participants may have been unaware that this study was time-sensitive. One recommendation

would be to increase the amount of time people had to be notified and have the opportunity to respond to the study by a certain end date so the study would be considered time-sensitive to end the recruitment process and expedite the interview process. Another recommendation would be to send out a reminder email to remind participants of the study and the end date for which they could participate.

*Recruitment Plan of Participants.* Another limitation that affected the outcome of the study was the type of recruitment plan that was utilized by the researcher and the staff assisting with the recruitment of participants. The added step of receiving permission from the recruiting agency as well as the additional reliance on this sole recruitment approach dispersed from the psychology staff was a limitation to the study. This researcher would recommend utilizing additional avenues of recruitment in order to broaden the amount of people who are exposed to the study and are able to participate. It would have been beneficial to include recruitment to parent and ASD advocacy groups who have list serves for their families as well as other agencies that serve families of children with ASD to increase the number of people exposed to the study. Additionally, because families could not be current clients from this researcher's clientele, this eliminated several families who would have fit the criteria and whose participation and input would have been valuable and meaningful to the purpose of the research.

It may be possible to include an incentive such as a monetary benefit for caregivers as a way to encourage their participation. Online surveys may be another way to increase participation because it does not require a participant to meet and interview with a researcher. These suggestions for future research may help broaden the methods in which participants are invited to participate.

*Number of Participants.* The number of participants that were involved in the study was a limitation. Three participants does not allow for the study to be generalizable to a larger



context or population. Similarities and differences can be inferred, but the small sample size hindered any additional information from being communicated from the interviews. Likewise, themes may have been strengthened if more participants expressed similar challenges or strategies and the opposite is true of different challenges and strategies that families used.

*Gender of Participants.* As previously mentioned, mothers tend to be the primary caregivers for their children with ASD. Because of this, fathers and other familial caregivers may not be equally represented in this study although all efforts to include these additional caregivers were taken into account.

## **Implications for Social Work**

### *Major Findings and Implications*

It is apparent that this research identified major themes among the interviews that were notable to the purpose of this study. First, all three families identified challenges that inhibited them from participating consistently with their child's treatment plan. These challenges included working during the times staff were implementing treatments, caring for other children during this time, and being available for trainings. These are real challenges that affect families and these factors were highlighted in this study. Social workers need to be cognizant of how these challenges affect families and their time spent working together as one unit. It is important to recognize that working with families at different hours of the day or week are essential to allow other parts of the family the opportunity to participate in the child's treatment.

Second, three out of three families discussed how they utilized different strategies to stay involved with their child's treatment plan. These strategies included involving other family members in the trainings and generalization of skills to promote more inclusion and consistency in program implementation. This is crucial information because involving other family members could be a tactic to use when training families in the skill acquisition. This also highlights the need for social workers and other professionals to become trained and skilled in the implementation of family skills in order to increase the effectiveness in training the caregivers. More so, social workers need to be aware that consistency in treatment and skill generalization can support more long-term skill maintenance for both the child and the family. This is essential for helping families become change agents for future behavioral changes and ensuring long-lasting learning.

It is evident that with the investigation of what challenges families face when participating in their child's treatment plan, that there are several extenuating factors that

clinicians, therapists, and social workers alike need to be concerned with. It has been clearly identified that there is a need to understand the challenges families face and to identify effective ways to remediate these challenges by establishing strategies to employ as an intervention. Because of this, professionals who provide these services need to continuously be sensitive to the challenges that families face when caring for a child with an ASD. Likewise, these professionals need to be aware of the importance of involving and training other family members in order to increase participation in treatment objectives and the success of the child and family. It is crucial as professionals to possess and refine their skills in training family members to implement the treatment objectives effectively.

By becoming aware of what barriers and challenges families face is imperative to providing more comprehensive, informed, and tailored services to our clients and their families. Additionally, knowing what assists families in being successful and effective are equally imperative to teach, support, and advocate for these families. Obviously, it is crucial to know what *does* work for families and what may be implemented for families who are experiencing challenges in executing their child's treatment plan. By focusing on a more strengths-based approach to supporting families of children with ASD, this will allow clinicians, therapists, and social workers to provide more sound support to the families they serve.

### **Conclusion**

This study aimed to identify challenges that families face when implementing their child's treatment plan. The identification of these challenges will help mental health professionals and therapists alike understand the issues families face in a real-life setting. This study identified real strategies, such as increasing participation of other family members, that families use and rely on to help integrate them into their child's proposed treatment plan. Professionals working with families will benefit from this research as it will highlight the strategies that families find useful in working with their child and their child's treatment team. This will aid in helping professionals better adapt and accommodate their approach to working with families. This research was conducted on families who are experiencing the process of ASD and their associated treatments, this research yielded information directly from the voices that are affected most by ASD. This research project contributed to the literature related to supporting families of children with ASD.

To summarize, the major themes that were identified among the participants included challenges in family involvement including working out of the home or being absent when staff were working in the home as well as physical, emotional, or psychological challenges that impaired a family's active participation. On the contrary, all families identified strategies that they utilized to increase their participation. These strategies included incorporating other family members and support systems into the training and implementation of treatment as well as prioritizing time to train with staff. Families reached out for more informal supports as a means to supplement their care-giving duties and skill development.

It is imperative to be aware of the challenges families face when implementing their child's treatment objectives and even more important to be sensitive to the hurdles families face. It is obvious that parental involvement is a key factor that contributes to the success of the

child and the family as a whole when the caregiver is consistent and participative in their treatment objectives. Family involvement and generalization of skills are extremely important to families that participated in this study and identifying ways to support families is the essence of sound social work practice.

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**Appendix A**  
Psychology Staff Approval Letter

**Marnie Tuenge Study Recruitment**

**Erin** Wed, Jan 7, 2015 at 12:27 PM

To: irb@stkate.edu

To whom it may concern,

We have agreed to send notices about Marnie Tuenge's research project to families who are served by (agency). The families will use the contact information provided on flyers to contact Marnie with questions or to participate. Marnie will not have access to protected health information from families, unless they choose to provide her with it directly.

Marnie Tuenge is a supervisor and direct service staff at (agency), and we have asked her to exclude families from the study for whom she also serves as staff at (agency) to avoid potential confusion by the families of what activities are (agency) and those that pertain to her research.

Please feel free to contact me with any additional questions about (agency) role in this research project.

**CONFIDENTIALITY NOTICE**

This message and any included attachments are from (agency) and are intended only for the addressee. The information contained in this message is confidential and may constitute Personal Health Information as defined by federal HIPAA or state medical records confidentiality regulations. Unauthorized forwarding, printing, copying, distribution, or use of such information is strictly prohibited and may be unlawful.



## **Appendix B**

### **Confidentiality & Consent Form**

#### **SUPPORTING FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER CONFIDENTIALITY AND CONSENT FORM**

**Introduction:**

You are invited to participate in a research study investigating the challenges and therapeutic strategies that families of children with autism spectrum disorder (ASD) face when implementing their child's prescribed treatment plan. This study is being conducted by Marnie Tuenge, a graduate student at St. Catherine University under the supervision of Michael Chovanec, PhD., LICSW a faculty member in the School of Social Work. You were selected as a possible participant in this research because you are currently care giving for a child with ASD. Please read this form and ask questions before you agree to be in the study.

**Background Information:**

The purpose of this study is to identify the challenges families face with implementing their child's family skills objectives as well as identifying strategies families use to empower themselves to actively participate in this treatment. Approximately 10 people are expected to participate in this research.

**Procedures:**

First, you will receive a copy of the flyer, the consent form, and the research questions pertaining to the study so you can review it before deciding to participate in the study or not. Second, if interested, you will contact the researcher to establish an interview time, date, and location for the interview to be conducted. Third, the participant will review and sign the consent form and fourth, the researcher will conduct the interview using the established questions. The interview will be audio taped for transcribing purposes. This study will take approximately 30 to 60 minutes to complete over the course of one session.

**Risks and Benefits of being in the study:**

The study has two identified risks. First, it is noted that this study may inconvenience some participants by taking time away from their family. In order to address and mediate this concern, this researcher has established three different ways that participants may complete the interview. The following ways include: St. Catherine University Collaborate technologies, phone interviews, and in-person interviews at the participant's most convenient time. Second, another risk may include emotional grief and stimulation for a caregiver who care gives for a child with a one year post-diagnosis of ASD. In the likelihood of this occurrence, additional resources will be made available for the caregiver. These resources include: emotional supports that are available to the caregiver and printed information regarding additional supports for families of children with an ASD diagnosis. Additionally, a debriefing will occur after the interview to check in with the participant about any emotional stimulation that may have occurred during the interview.

There are two benefits to participation in this research study. Your participation will help professionals working with families of children with ASD know what some of the challenges

are that families face and how it can impact treatment. Second, you will help professionals identify effective strategies that assist families in being more invested in their child's family skills objectives.

There are no monetary benefits for your participation in this research study.

**Confidentiality:**

Any information obtained in connection with this research study that can be identified with you will be disclosed only with your permission; your results will be kept confidential. In any written reports or publications, no one will be identified or identifiable. The agency from which you receive services will not be made aware of your participation in this study.

We/I will keep the research results in a secure USB drive in a locked safe and only Michael Chovanec and I will have access to the records while we/I work on this project. We/I will finish analyzing the data by May 1, 2015. We/I will then destroy all original reports and identifying information that can be linked back to you after the completion of this study no later than June 1, 2015.

**Voluntary nature of the study:**

Participation in this research study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of St. Thomas and St. Catherine University in any way nor will it affect your relations with the agency from which you receive services. If you decide to participate, you are free to withdraw at any time without affecting these relationships or incurring any penalties.

**Contacts and questions:**

If you have any questions, please feel free to contact me at (651)-207-3887 or at [tuen6516@stthomas.edu](mailto:tuen6516@stthomas.edu). You may ask questions now, or if you have any additional questions later, the faculty advisor, Michael Chovanec will be happy to answer them. You may reach him via phone at (651)-690-8722 or via email at [mgchovanec@stkates.edu](mailto:mgchovanec@stkates.edu). If you have other questions or concerns regarding the study and would like to talk to someone other than the researcher(s), you may also contact Dr. John Schmitt, Chair of the St. Catherine University Institutional Review Board, at (651) 690-7739 or [jsschmitt@stkate.edu](mailto:jsschmitt@stkate.edu).

**Statement of Consent:**

You are making a decision whether or not to participate. Your signature indicates that you have read this information and your questions have been answered. Even after signing this form, please know that you may withdraw from the study.

I consent to participate in the study and to be audio taped for transcription purposes.

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Signature of Participant

Date

---

Signature of Researcher

Date

**Appendix C**  
Research Questions

**SUPPORTING FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER**

**Instructions:** Please fill out the following questions completely and to the best of your ability.

**Gender:**

- ☐ Male  
☐ Female  
☐ Prefer not to answer

**Race/ethnicity:**

- ☐ African American/Black  
☐ Caucasian/White  
☐ Hispanic/Latino  
☐ Asian  
☐ Native American/Alaska Native  
☐ Native Hawaiian or Pacific Islander  
☐ More than 2 races/other: \_\_\_\_\_

**Age:**

- \_\_\_\_\_ (of child)  
\_\_\_\_\_ (of caregiver)

**Relationship to child:**

- ☐ Mother  
☐ Father  
☐ Grandparent  
☐ Other: please explain \_\_\_\_\_

**Relationship status:**

- ☐ Single  
☐ Married  
☐ Divorced  
☐ Widowed

**1.) What challenges, if any, have you faced when implementing your child's family skills training objectives?**

**2.) What have you found most challenging about implementing your child's family skills training objectives? How did you address this concern?**

**3.) In what ways, if any, have these challenges affected your child? Your service providers? Your community?**

**4.) On a 1 to 5 scale how would you rate these challenges? (Please circle one answer)**

1 (not at all)

2

3

4

5 (extremely)

**5.) What strategies have you used that help you become more participative in your child's treatment objectives?**

**6.) On a 1 to 5 scale how would you rate these strategies as effective in implementing your family skills training objectives? (Please circle one answer)**

1 (not at all)

2

3

4

5 (extremely)

**7.) What assistance would you like to receive that you would find effective in helping you implement your child's treatment objectives?**

**8.) Are there any elements of your culture that affect you/your child that impact your ability to implement your child's treatment? What would you recommend to service providers?**

**9.) Is there anything else you find useful or relevant to share for the purpose of this research?**

**Thank you for your time! Your contribution has made this research possible!**